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## HIV in the Late 1990s: What We Don't Know May Hurt Us

In this issue of the Journal, Karon and his colleagues at the Centers for Disease Control and Prevention (CDC) present new data on trends in the HIV/AIDS epidemic in the United States during the 1990s.<sup>1</sup> To appreciate the scientific challenges that have been surmounted to obtain this update, it is helpful to review how CDC experts gauged the size and direction of the epidemic in the past.

Prior to the era of highly active antiretroviral therapy (HAART), CDC used “triangulation.”<sup>2</sup> This approach synthesized 3 complementary and independent sources of information: (1) AIDS surveillance data, coupled with deconvolution methods known as “back-calculation,” which allowed one to reconstruct historical HIV incidence from the numbers of reported AIDS cases; (2) the national Survey in Childbearing Women, which provided a direct estimate of HIV prevalence among women of childbearing age; and (3) the Third National Health and Nutrition Evaluation Survey (NHANES III), the “nation’s health survey,” which also provided a snapshot of HIV prevalence in the general population.<sup>3</sup> An important point is that no single source of information was deemed sufficiently reliable to serve as the sole basis for tracking the epidemic.

### *New Methods for Monitoring the Epidemic*

Events overtook this approach. With the widespread use of HAART since 1996, it has become essentially impossible to do back-calculation, because AIDS trends no longer reflect the natural history of the disease. The national Survey in Childbearing Women, which had been the jewel in the crown of the national Sentinel Seroprevalence Surveys, was suspended in May of 1995 for what may have been political reasons. Finally, as designed, NHANES III finished enrolling subjects in 1994. Therefore, since 1995 we have had to endure a “window of uncertainty,” with relatively little new information to tell us where the HIV epidemic was going.

Fortunately, CDC scientists have developed new approaches. Karon and his colleagues’ current report presents the first national synthesis of these efforts, along with an in-depth analysis of the latest trends in AIDS case reports.

One of the new approaches is based on “named HIV reporting.” In some states, a diagnosis of HIV infection is reported to local health officials, using the same confidential case reporting system that is used to track

AIDS diagnoses. Karon et al. describe results from 25 states that had named HIV reporting as of 1994, mostly in the Southeast. As of July 2000, 21 states (with 58% of all AIDS cases) had not implemented named HIV reporting.<sup>4</sup> Therefore, this approach does not yet provide a national picture.

The other new approach couples “venue-based” sampling<sup>5</sup> with the serologic testing algorithm for determining recent HIV seroconversion (STARHS; sensitive/less sensitive HIV assay).<sup>6</sup> This serologic approach can discriminate recently infected individuals. The combination of these 2 approaches is innovative and provides us with new estimates of HIV incidence in targeted at-risk populations. Using standard HIV antibody assays, CDC’s earlier “family of surveys” estimated the prevalence of HIV infection but not the more crucial parameter, which is HIV incidence. In this regard, the new approach represents an important advance.

### *Is the Glass Half Empty or Half Full?*

In the synthesis of Karon et al., we learn that there is no evidence that HIV incidence

in at-risk groups is declining. HIV incidence among men who have sex with men has been approximately 2% per year; the incidence of infection among injection drug users has been somewhat lower but still high. Viewed optimistically, these rates are dramatically lower than rates in the early to mid-1980s, when upward of 10% of high-risk individuals became infected each year. Nonetheless, at these rates infection will not be a rare event among persons who continue to engage in risky behavior over several years.

In contrast to the plateau in HIV incidence, AIDS deaths have declined dramatically over the same period, thanks to HAART. As Karon et al. remind us, communities should not equate this decline in deaths with a decline in new HIV infections or an end to the epidemic. HAART does not eradicate HIV from the body, and no one knows whether the drugs can be tolerated and will work indefinitely. For individuals with severe immunosuppression, even with HAART the risk of death is about 1 in 11 per year.<sup>7</sup> This is a major decline from the corresponding death rate of about 1 in 3 during the pre-HAART era, but it still represents a grim future.

Karon and his colleagues' analysis also suggests that poorer, disproportionately African American communities may have had less access than others to HAART therapy. Limited access may result in a double tragedy. It is a tragedy for individuals who get suboptimal care. It may also be a tragedy for communities, because therapy that reduces HIV viremia—often to undetectable levels—probably reduces infectiousness. In addition, because patients under treatment visit their physicians frequently, they have an opportunity to receive counseling on how to reduce the chance of transmitting their infection to others.

### ***The Available Data Have Gaps***

While the new data presented by Karon et al. advance our understanding of the epidemic, it is an unfortunate fact that in many ways we know less about the epidemic than we did 5 years ago. Five years ago we knew that about 130 000 women in the United States were living with the infection (as of 1992).<sup>2</sup> How many women are living with the infection in 2001? We simply don't know for sure. Similarly, one of the most often quoted sta-

tistics about the AIDS epidemic is that about 40 000 Americans become infected each year. In fact, this figure is a reasonable consensus estimate for the early 1990s. What's the rate in recent years? We simply don't know.

Karon et al. are acutely aware of the limitations of our existing surveillance system. CDC has recommended that all states carry out named HIV reporting,<sup>8</sup> as have others.<sup>9</sup> Resistance to this proposal reflects concerns about privacy. Whatever one's opinion of the merits of these concerns, they have made it much harder to track the epidemic during the late 1990s, because CDC has not been able to count all the cases.

At least we can look forward to new data from NHANES IV. This comprehensive health survey commenced in 1999 as a rolling survey of 5000 participants per year, with HIV testing of subjects 18 to 49 years old (Geraldine M. McQuillan, PhD, [gmm2@cdc.gov], e-mail, January 10, 2001). The combination of national named HIV reporting, NHANES IV, and targeted seroincidence surveys using STARHS could provide a robust triangulation method of the type that has proven so useful in the past. Each individual approach will be subject to uncertainty owing to biases and statistical imprecision; thus, the most credible future assessments of the epidemic will derive from the synthesis of multiple independent sources of information.

Is the epidemic in the United States slowing or growing? Karon et al. suggest that at least it is not increasing rapidly. We know that prevention can work. By the early 1990s HIV incidence had slowed substantially among young White homosexual men in the United States,<sup>10</sup> and incidence has also slowed among injection drug users in New York City.<sup>11</sup> In contrast to these positive trends, HIV prevalence remains alarmingly high among racial and ethnic minorities, and heterosexual contact has become the leading cause of infection among young women.<sup>10</sup> This is the deceptive stability of an epidemic in transition: declines in one group are matched by increases in another.

As Karon et al. document, during the 1990s the epidemic increasingly affected women, racial and ethnic minorities, and the poor, but during the same period it became harder to measure. The available data have gaps. As a consequence, our knowledge is limited, and that is not good news. □

*Philip S. Rosenberg, PhD*

The author is with the Division of Cancer Epidemiology and Genetics, National Cancer Institute, Rockville, MD.

Requests for reprints should be sent to Philip S. Rosenberg, PhD, Division of Cancer Epidemiology and Genetics, National Cancer Institute, 6120 Executive Blvd, EPS 8020, Rockville, MD 20852 (e-mail: philip\_rosenberg@nih.gov).

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